

**GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA**

UNSTARRED QUESTION NO:1238
ANSWERED ON:31.07.2000
THALASEMIA DISEASE
JAI PRAKASH

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

- (a) whether the Government are aware about the spread of fatal disease like Thalasemia in various States particularly in West Bengal;
- (b) if so, whether the Government propose to make it mandatory to conduct a test for the said disease before marriage so as to prevent it at initial stage;
- (c) if so, the details thereof;
- (d) if not, the reasons therefore; and
- (e) the steps taken by the Government for the prevention of the said disease?

Answer

THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (PROF. RITA VERMA)

(a) As per study conducted by Indian Council of medical Research at 3 centres viz. Delhi, Bombay, Calcutta, the prevalence of beta-thalassaemia trait was found to be 2.7% in Bombay, 5.5% in Delhi and 10.2% in Calcutta amongst 12,047 children screened in different schools. Hence, it cannot be said with authority that thalassaemia is spreading.

(b) to (e) The requisite information is given in the Statement attached at Annexure - A.

ANNEXURE A

STATEMENT REFERRED TO IN PARTS (b) TO (e) OF THE LOK SABHA UNSTARRED QUESTION NO.1238 FOR 31.7 RELATING TO THALASSAEMIA DISEASE ASKED BY SRHI JAI PRAKASH

(b) to (e) : There is no such proposal under consideration of the Govt. However, a research project entitled `Community control of thalassaemia syndromes-awareness, screening, Genetic counselling and Prevention` has been initiated by Indian Council of Medical Research with effect from 1.3.2000

The project aims at education, screening, counseling and identifying couples at risk of having thalassaemia children so as to prevent birth of these children and developing a national referral centre for control of thalassaemia major in the country. Study is being carried out on college students and pregnant women. The project has been launched in 6 States including Maharashtra, Gujarat, Assam, West Bengal, Punjab and Karnataka. The investigating centres include Institute of Immunohaematology, Mumbai (ICMR), Baroda Medical College, Vadodar, RMRC, Dibrugarh (ICMR), Calcutta Medical College/NRS Medical College, Calcutta, Christian Medical College, Ludhiana/ St. John's Medical College/ Rotary Blood Bank, Bangalore. The responsibility of these centre include:

1. Screening of high risk communities in respective States to detect B. Thalassaemia trait and estimate prevalence in those areas.
2. Screening of pregnant women to be carried out in early pregnancy for beta thalassaemia trait. If the pregnant women is heterozygous with beta thalassaemia trait, the husband will also be screened for this trait. If both are positive, then prenatal diagnosis will be carried out and advised accordingly. Genetic counselling and availability of prenatal diagnosis will be indicated to the couple if both are carriers of beta thalassaemia trait. Other than this, centres may also provide genetic counselling to general population in high risk communities who may not be of reproductive age but may help in dissemination of information, pre and post marriage counselling of youth and pre and post natal counselling for at risk couples. These centres will also look after the blood transfusion programme, which will include availability of safe blood and teach patients how to use infusion pump or chelating agents for therapy.